

Peer support

It's helped me tremendously, getting information and having a laugh with people who have been through it too. I'm no longer just sitting at home thinking 'I'm alone, what can I do? I'm stuck'.

I feel more confident about standing up for my rights and not accepting second-rate service.

I have learnt loads. The biggest thing I have learnt is how to look at myself differently. Learning about the social model of disability has been the biggest learning for me.



**Activity and outcomes report for the
LCiL capacity building programme
for disabled people and
people with long-term conditions**



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Introduction



'Before coming to LCiL groups for the first time I didn't even know what I was entitled to. I didn't have a clue because nobody would tell me. At the group everybody talks to each other so you find out useful things that can help.'

This booklet was put together by LCiL's Self Directed Support (SDS) Capacity Building Programme, which aims to build individual skills, knowledge, confidence and resilience so that people are self-empowered to live the lives they want and be more in control.

In Part 1 we share the results of an evaluation that was undertaken with disabled people and people with long-term conditions who attend workshops and peer support groups hosted by LCiL. The evaluation involved 15 people who regularly attend these groups. Although this is a relatively small number of people we believe they represent a fairly wide and typical range of experience. The size of the evaluation group also allowed us to explore their engagement with peer support more deeply than we could have done with a large group.

By sharing the evaluation results we aim to:

- illustrate the power and value of peer support and how this can support individuals to be self-empowered
- highlight how much people value the opportunity and time to share information and support each other
- give an insight into the difficulties and barriers people face when trying to get information and support

In Part 2 we have included details of why and how we set up peer support groups and how we host and facilitate them. Part 2 also includes workshop descriptions and information on what we've learned so far. We hope this will give others who want to set up something similar enough information to do so.

Emma Wynack and Debbie Bayne
June 2017

The social model of disability

The **social model of disability** says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

Disabled people developed the social model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.

Barriers are not just physical. Attitudes found in society based on prejudice or stereotype also disable people from having equal opportunities to be part of society.

The social model of disability says that disability is caused by the way society is organised. The **medical model of disability** says people are disabled by their impairments or differences.

Under the medical model, these impairments or differences should be 'fixed' or changed by medical and other treatments, even when the impairment or difference does not cause pain or illness.

The medical model looks at what is 'wrong' with the person, not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their own lives.



'Learning about the social model of disability has been the biggest learning for me, it's like I always thought like that, but now it's really clear to me.'

'I had never thought in terms of the social model before, especially how it could relate to people with mental health.'

Summary



Since February 2016 32 people have attended one or more of the three LCiL peer support groups. Of these, 12 people have attended six or more times and 20 people have attended three or more times. A total of 72 people who have attended workshops or peer support groups have requested to be kept informed of meeting dates and topics.

There were a total of 14 peer support group meetings between February 2016 and March 2017.

The groups are participant-led but organised, hosted and facilitated by LCiL staff, whose role is to serve, but not be part of, the group.

During meetings of the groups we hear from people about the issues they face – as disabled people or people with long-term conditions, and in accessing information and support. We gained experience and knowledge of how to create and facilitate an effective peer support group. The evaluation we carried out, and what people told us during group sessions, identified a series of positive outcomes.

'Getting knocked back time and time again when I have asked for help and support has really affected my confidence. No one tells you anything and then when you ask you are made to feel bad or that you are not entitled.'

Issues

- People need **good quality communication:** the right information, at the right time and in the right format *for them*. Often this doesn't happen, especially if people are facing a crisis of some kind. This applies both to information about what support is available and to what local authority social care processes are and how to navigate them.
- There is **a lack of support**. Some people who clearly need support are unable to access it – either because they don't know how to get into the system, or because eligibility criteria or poor quality assessment systems exclude them

Issues cont'd

- There is considerable **anxiety about social care assessments** and reassessments. People do not experience the person-centred, collaborative assessment mandated by the SDS Act, and often get insufficient or inappropriate support for their needs
- People **lack the confidence and skills** to deal with the **power imbalances** in the system to get and manage good support and often put up with inadequate or inappropriate support. There is a lack of advocacy services and where these do exist people often don't know how to access them.
- People want **meaningful activity** in their lives, such as **work, volunteering or learning** opportunities but these are hard to find.
- **Money is often an issue** – the benefits system is hard to navigate and inconsistent. Without information and specialist support people are sometimes unable to access what is theirs by right.
- **Isolation and loneliness** are an issue for many people, especially those without enough support to be able to get out and engage with their local community.
- All of these issues impact on people's **physical and mental health**, and their overall wellbeing.

Outcomes

People told us that they were:

- now asking for help or support
- taking more control over their lives and/or their support
- asserting themselves and not 'letting things go' if they weren't happy with service they received or the way their support was delivered

Summary



'I didn't know how to get out of the situation I was in, I didn't know who could help, and it was affecting how my brain worked. I actually felt stupid when I was trying to deal with benefits and housing, but I know I'm not! If it wasn't for the support of LCiL and the group when I moved local authorities, I wouldn't have known what to do.'

Summary



'I think the way they're put together is great. The check-in part is really important. I've found at other groups I've been to you don't always get that, you get spoken at. I like how the group is there for people to share what's going on, but also celebrate successes.'

Outcomes cont'd

People told us that they were:

- less isolated – that had more contact with people and were generally getting out and about more
- volunteering or job seeking or getting involved in other groups or consultations

And that they felt:

- more confident
- more determined
- more relaxed
- happier (a lot of people said this)

What makes it work

People told us that the groups work well because they are:

- owned by the group but hosted and facilitated by neutral workers who don't have an agenda
- welcoming, comforting, friendly and relaxed. A place where it's okay to talk about difficult things, but where it's also possible to have fun
- balanced – with time to share peer to peer, and time to hear from expert guest speakers
- small enough to allow people to speak, and not to feel overwhelmed

and because of the practicalities, including:

- having a personal assistant (PA) to help support people
- being able to eat lunch together
- the start time being late enough to allow people with inflexible support packages or long morning routines to attend.

Part 1



Evaluation

Mark's story: finding my voice



At first it was very hard for me to open up in front of the group, but because I felt comfortable and accepted I kept coming back.

'When I first came to the peer support group I didn't speak, but now I've managed to open up. At first it was very hard for me to open up in front of the group, but because I felt comfortable and accepted I kept coming back. [In the peer support group] I get to put my point across. I get to speak to people, I don't get to do this when I'm at home. Sometimes it can be difficult to bring something up, but it gets easier the more I speak at the group

My mum had control over everything, she would do everything for me and I had no clue what was going on. Now I want to be independent. It is all learning, if I make a mistake I will learn from it, but I want the chance. I have asked social work to help me be more independent, it is taking a long time.

Before I was in the group if I wanted to learn about something I would have to ask my family. I have now started to find out about college. For me it is like a jigsaw puzzle, I just need all the pieces to come together, [living independently in] my house and going to college is part of that. I would like to study IT or cooking and baking. If I do study cooking I will need to get my kitchen made more accessible, my social worker is going to help me with this.

Mark's story: finding my voice

I like the fact that people come in with different ideas, you learn so much from others in the group. There are points where people come in and talk about so many different things that also happen to me, like wheelchair access, how to get good support. Hearing information from others in the group helps me become more independent, for example hearing about access is very important, if it's not accessible it cannot happen.

I'm now looking to the future. I want to be independent. I don't want to have my mum to control everything for me, it's hard but I want to be in control. I'm gradually getting there. At first I wasn't sure if it was going to work, but the group helps me see that it is working and all the hard work is worth it

I am trying to be independent as I can, so I am taking small steps towards this. Talking to different people and hopefully making friends is part of that. For me it's a learning curve. I don't want to go back to what it was like, I want to go forward.'



I don't want to go back to what it was like, I want to go forward.

A snapshot of a group



Peer support groups meet once a month, for two hours, followed by lunch. At most meetings the first hour is time for people to catch up, share their stories and exchange information. The second hour is sometimes a brief talk, followed by discussion, with a guest speaker.

At any session a group could be made up of:

I now know if there is a problem with my benefits or my house I can find out who can help me sort it out, I don't have to just sit in the house worried and stressed out about it.'

Malcolm – lives in his own flat. Has direct support from an agency.

Alma – lives in her own flat. She moved to Edinburgh to come to university and had her support package transferred from another local authority. She volunteers and is exploring paid work options. Has a direct payment and uses an agency.

Natalie – has recently moved house from one local authority area to another. She is currently getting her new home adapted to meet her needs. No support package.

Learning to be assertive for myself was huge, it still isn't always the easiest, but it has helped me come so far.'

Don – has lived in his own tenancy for more than twenty years. He's a keen photographer and loves being outdoors. He wants to work but can't find a job. He has housing support.

A snapshot of a group



Mike – lives in his own flat. He recently took over control of his support and is exploring employing personal assistants and volunteering. Has a direct payment and uses an agency.

Kim – lives with her parents. She had to give up study because the college couldn't meet her support needs. She uses a direct payment to employ personal assistants.

Linda – has recently moved into her own house from a shared tenancy. She has a small amount of direct support.

Carol – stopped work because of her condition but now wants to change career direction. No support package.

Pat – works part-time but wants to find a job that's better for her health. No support package.

*After coming to the peer support group I started to think that I could try to find another job.
A job that suited me and was doing something I like.*

(Names and details have been changed to preserve confidentiality, but this is representative of the make-up of a typical group)

The evaluation



'I hadn't started to learn new things because my self-esteem was low. I wouldn't go to any groups or classes because I was embarrassed to go out in public. I had locked myself away.'

Stages of empowerment

Stage 1

Stuckness/apathy/fatalism

believing that it's impossible

'it can't be changed, this is my lot, it's just the way it is'

Stage 2

Having a vision for change

believing that it's possible

'it can be changed, there are possibilities'

Stage 3

Acting for change

knowing it's possible

'I'm doing something(s) to change it'

Stage 4

Continuing to act in difficult circumstances

being tested

'I'm still doing something even though it's hard. I'm determined and will fight to change it'

Stage 5

Acting as an example

showing it's possible

'I'm encouraging/supporting others to change it for themselves'

Stage 6

Organising action

making it possible for others

'I'm organising and leading action to help others to change it'

We use the stages of empowerment both as a way of understanding how people move towards greater self-empowerment and to underpin our activity and the way we evaluate distance travelled and achievement of outcomes.

The evaluation

Building on previous work we had done to evaluate our parent and carer peer support group, we designed a questionnaire which asked people to mark the statement that was closest to how they felt **before they came to a peer support group or workshop** and the statement that was closest to how they felt **now** under six topic headings:

- knowledge of support available
- contact with others in a similar situation and developing new friendships
- confidence to ask for support or change
- learning new things
- trying new things
- supporting others and forming a collective voice

For each of the six topics in the evaluation questionnaire we wrote a statement that matched each stage of empowerment. This gave us an indication of distance travelled.

The questionnaire also asked about:

- what difference being part of a peer support group made to how people felt and to what they were doing
- how well the practicalities of how the peer support groups were hosted and facilitated worked

Some people filled in the questionnaire and returned it. With others it was used as the basis for structured interviews. The information that follows is collated from 15 completed questionnaires.

We also wrote up two stories of people's experience of the difference peer support has made to them (see pages 10 and 36)

Note: in the following pages '**group**' means a **peer support group or a workshop**.



'LCiL supported me to become more empowered, I love learning and now I'm not afraid to take up opportunities and throw myself into new situations. The need for progress and being allowed to be me is stronger than the fear I used to have.'

Overview of responses



'I've changed as a person, but I've also made connections with new people. These connections are supporting me to think about the future. After what happened at work I couldn't think about the future, I was completely stuck. I'm now thinking about the possibilities.'

1. Knowledge of support available

- **Before** coming to a group 7 out of 15 people didn't know what support was available or how to access it. Only one person was helping others to access support.
- **After** coming to a group 12 people were accessing support, telling others about what support is available, or helping others to access it.

2. Contact with other people in a similar situation and developing new friendships

- **Before** coming to a group 7 out of 15 people had no contact with others in a similar situation. No-one was telling others about peer support groups.
- **After** coming to a group 10 out of 15 people were telling others about groups or organising times to meet with others to share information and support

3. Confidence to ask for support or change

- **Before** coming to a group 5 people wouldn't ask for support or change if something wasn't working, and only 5 people knew they had a right to ask for support or change.
- **After** coming to a group 9 out of 15 people had encouraged others to ask for support or change in support or had spoken up on behalf of others

Overview of responses

4. Learning new things

- **Before** coming to a group 10 out of 15 people didn't think they could learn new things or thought they might be able to but didn't know where to start. Only one person said that they felt confident to support others to learn new things.
- **After** coming to a group 8 people were supporting others.



5. Trying new things

- **Before** coming to a group only 5 out of 15 people were trying new things
- **After** coming to a group all but one person were trying new things

6. Working together with others for change (collective voice)

- **Before** coming to a group 3 people didn't believe things could be changed by working with others and only 3 people were encouraging or organising action.
- **After** coming to a group everyone said there was at least the possibility for change, and 11 out of 15 had at least started working with others towards change

'I'm an activist now, I attend rallies and events. I wouldn't have been able to do all this without LCiL, it reinforced something in me. It boosted my confidence and now I'm no longer someone stuck in my house, afraid to voice my opinions.'

Overview of responses



'I feel a lot more happier and relaxed. Before I got support from the group I used to snap at people and get angry, even at my family. Now when things are going wrong I can look at the bigger picture, I can think it's not as bad because I can go to the group and share it.'

The difference that peer support made to what people did

People told us that they were:

- now asking for help or support
- taking more control over their lives and/or their support
- asserting themselves and not 'letting things go' if they weren't happy with service they received or the way their support was delivered

The difference that peer support made to how people felt

People told us they felt:

- more confident
- more determined
- more relaxed
- happier (a lot of people said this)

The practicalities of how workshops and groups were facilitated

People told they work well because they're:

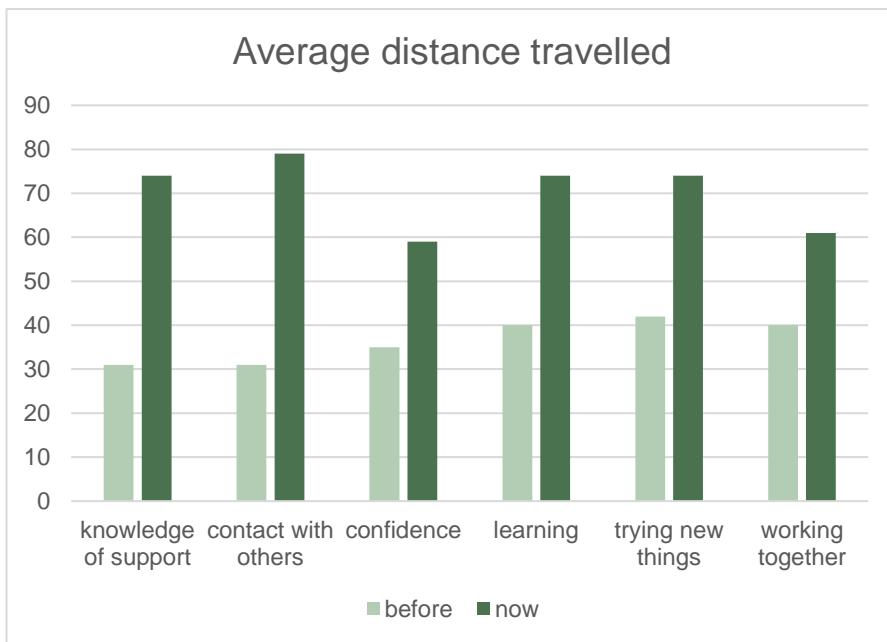
- owned by the group but hosted and facilitated by neutral workers who don't have an agenda
- welcoming, comforting, friendly and relaxed. A place where it's okay to talk about difficult things, but where it's also possible to have fun
- balanced – with time to share peer to peer, and time to hear from expert guest speakers
- small enough to allow people to speak, and not to feel overwhelmed

and because of the practicalities, including:

- having a PA to help support people
- being able to eat lunch together
- the start time being late enough to allow people with inflexible support packages or long morning routines to attend

Overview of responses

Each person's response to each question was given a score from 1 to 6 (with 6 being the most empowered). These scores were added up to give a total for 'before' and a total for 'now'. Below is a bar chart showing average distance travelled for each question.



'My attitude has now completely changed. I have now met other people through the groups who affirm that it's okay to speak up if you think something isn't right.'

Detailed responses to the questionnaire follow.

Note: In the 'before' and 'now' tables people were asked to mark the statement in each column which was closest to how they felt.

Each dot - • - represents a single individual's response to that statement.

1. Knowledge of support available

Before I was in a group		Now	
I didn't know what support was available	I don't know what support is available	
I knew that there was support, but didn't know how to access it	I know there is support available, but I don't know how to access it	
I had started to find out what support was available	•	I have started to find out what support is available	
I had started to access support	•	I have started to access support	...
I was telling other people what support was available		I am telling other people what support is available
I was helping others to access support by sharing tips and what had worked for me	•	I am helping others to access support by sharing tips and what had worked for me

Key points

- People's knowledge increased dramatically through taking part in the groups
- People value sharing with each other and learning from each other's first-hand experience of services and processes
- People are keen to share what they know with others

'Before coming to LCiL groups for the first time I didn't even know what I was entitled to. I didn't have a clue because nobody would tell me. At the group everybody talks to each other so you find out useful things that can help.'

'Because of the group, I was able to contact the Cyrenians and occupational therapy as soon as I moved to get the support I needed. In the past, I was not confident enough to make contact with organisations on my accord and would avoid doing it. Now I can pick up the phone tell them what I need and ask what they can support with, I would not have been able to do that without LCiL.'

'I often share with others information around the social care assessment. How to deal with incompetence, how to express what you need and what paths to go down. I am always telling others in the group to never give up.'

'I feel like I have been through all the stages [of empowerment]. Because the system changes so quickly, one minute I would feel I had a grasp of it and the next minute I would be completely lost and out of my depth. If it were not for the support of LCiL and the group when I moved local authorities, I would not have known what to do.'

'LCiL is the only place where there is a group that I can come to and talk about one of my conditions. I wouldn't be finding out all this information if I wasn't part of the peer support group.'

'There are lots of people in my life that need support and now I know much more about what is out there I can tell them about it. I don't always give specifics, but some people just need a little encouragement, hear it from somebody who's been there too.'

2. Contact with other people in a similar situation and developing new friendships

Before I was in a group		Now	
I didn't have contact with other people in a similar situation to me	I don't have contact with other people in a similar situation to me	
I knew that there were places/groups that I could meet other people in a similar situation to me	I know that there are places/groups that I could meet other people in a similar situation to me	.
I had started to find out about opportunities where I could meet with people in a similar situation to me		I have started to find out about opportunities where I could meet with people in a similar situation to me	
I had contact with people in a similar situation to me	I have contact with people in a similar situation to me
I was telling other people about the peer support group and other opportunities for disabled people and people with long term conditions to get together		I am telling other people about the peer support group and other opportunities for disabled people and people with long term conditions to get together
I was organising times to get together with other people to share information and support		I am organising times to get together with other people to share information and support

Key points

- People are less isolated when they are part of a group
- In the groups people feel accepted, regardless of their situation or impairment
- Many people have formed friendships that continue outside of group meeting times

'Spending time with other disabled people and making new friends has made me feel more comfortable and my own situation easier to deal with.'

'I find making new friends quite hard because of my upbringing. Because I have a learning disability I was bullied a lot. I look at myself as normal. When I come to the groups I feel accepted by everyone.'

'I'm now meeting up with people from the group outside of group meeting times. Even when the groups or workshops aren't happening I continue to give and receive peer support.'

'It's helped me tremendously, getting information and having a laugh with people who have been through it too. I'm no longer just sitting at home thinking "I'm alone, what can I do? I'm stuck".'

'Meeting people through the groups has taught me that there are so many of us going through the same experiences and coming up against the same problems. We all have different approaches and it's good to learn things from other people.'

'It has been so enjoyable coming here, the group keeps my head above water. In the past when things have got bad I have just left, I had a place in [another city] and when things got really bad I just packed up and left because I didn't have any support. There are times where I feel like doing this because of all the problems, but I haven't because I know I have the group.'

3. Confidence to ask for support or change

Before I was in a group		Now	
If something wasn't working or I needed support I wouldn't ask for it	If something isn't working or I need support I don't ask for it	
I thought there must be possibilities to get support or change something that wasn't working	I think there are possibilities to get support or change the things that aren't working	
I knew that it was my right to ask for support or change	...	I know that it is my right to ask for support or change	...
I had asked for support or change, but found it difficult	..	I ask for support or change, but can still find it difficult	...
I encouraged others to ask for support or change		I encourage others to ask for support or change
I spoke up on behalf of other people in the same situation as me and tried to influence change	.	I speak up on behalf of other people in the same situation as me and try to influence change	...

Key points

People's confidence has been improved through hearing:

- what their rights are and what is available – information
- what support others have and what they've done in a similar situation – seeing what's possible – often before people didn't ask for something or try to get something changed because they assumed the answer would be 'no'

This improvement in confidence has allowed people to act:

- to ask for support
- to ask for change or to get their rights met
- and, where necessary, to complain

'Coming to LCiL I realised I could be getting better support, that's why I am taking back control of my finances and becoming a PA employer.'

'In the past I would just drop it and give up. The peer support group has helped me keep going with what's been happening at work. This situation is still particularly hard, but I keep going back to them and telling them that they aren't treating me right and I ask for help from the union.'

'My attitude has now completely changed. I have now met other people through the groups who affirm that it's okay to speak up if you think something isn't right.'

'I encourage others to take things forward if something isn't right. People shouldn't have to put up with bad support or care. I tell people to find out what their rights are and don't do it by yourself, get advocacy or LCiL involved at the start.'

'Since coming to the groups I now can tell my support workers what I want to do. Sometimes I would say to my support worker that I wanted to do something and then the next week they would show up and refuse to do it, because they couldn't be bothered. Now I remind them of what I want to do and don't stand down.'

'This is where my confidence has grown the most. I now know if there is a problem with my benefits or my house I can find out who can help me sort it out, I don't have to just sit in the house worried and stressed out about it. Sometimes in the past if I did try to get help I wasn't sure how to access it or I was put on waiting lists and it never really worked out.'

4. Learning new things

Before I was in a group		Now	
I didn't think I could learn new things	...	I don't think I can learn new things	
I thought I might be able to learn new things, but didn't know where to start	I think I could learn new things, but I don't know where to start	•
I knew I could learn new things and had started to find out what opportunities were out there		I know that I could learn new things and I have started to find out what opportunities are out there	••
I had started to access opportunities where I am learning new things	...	I have started to access opportunities where I am learning new things	••
I was encouraging other people to learn new things by sharing my experiences and was getting positive feedback	•	I am encouraging other people to learn new things by sharing my experiences and am getting positive feedback	••
I felt confident to share my experiences and support other people to learn new things	•	I feel confident to share my experiences and support other people to learn new things

Key points

People value the opportunity to learn from and with each other, and from each other's experience.

Learning is:

- practical – about how support or benefits work
- gaining skills – such as being assertive
- around understanding the social model of disability and people seeing themselves and their situation differently in light of that understanding

'I don't know what was first, my confidence growing and then finding out new things, or learning new things has made me more confident.'

'I have learnt loads. The biggest thing I have learnt is how to look at myself differently - learning about the social model of disability has been the biggest learning for me.'

'LCiL supported me to become more empowered, I love learning and now I am not afraid to take up opportunities and throw myself into new situations. The need for progress and being allowed to be me is stronger than the fear I used to have. I have learnt so many skills through the groups and I use these every day. Learning to be assertive for myself was huge, it still isn't always the easiest, but it has helped me come so far.'

'From the group I have learnt to ask questions and not to give up. If there is something I don't understand I will ask the person to explain it to me instead of just being in the dark all the time.'

'One major learning for me over the last year is if you can't accept it, how will it change? I try to lead by example, there are things about me that I know I can't change and will just have to live with for the rest of my life, but that doesn't mean I can't have a good life and do the things I want to do.'

'In the group I learn so much from all the different people, I have never mixed with so many different people before. Everybody brings their experience, that's what I'm learning from the most.'

5. Trying new things

Before I was in a group		Now	
I didn't have the confidence to try new things	••	I don't have the confidence to try new things	
I wanted to try new things, but I didn't know where to start	•••••	I want to try new things, but I don't know where to start	
I wanted to try new things and started to find out what opportunities were out there	••	I want to try new things and I have started to find out what opportunities are out there	•
I had started to try new things by attending workshops and groups	••	I have started to try new things by attending workshops and groups	•••
I was encouraging other people to try new things by sharing my experiences and was getting positive feedback	••	I am encouraging other people to try new things by sharing my experiences and am getting positive feedback	•••
I felt confident to share my experiences, suggest ideas and support other people to try new things	•	I feel confident to share my experiences, suggest ideas and support other people to try new things	•••••••

Key points

- People get encouragement and motivation from hearing what others are doing – ‘if they can, I can too’
- There are practical as well as psychological barriers to trying new things – things like geography and lack of transport can get in the way
- Even people who are already trying new things can stretch their horizons even further with support from other group members – for example to try to get into, or back into, work

‘LCiL has helped me to push myself to try other things, sometimes outside of my comfort zone, but always to my benefit.’

'In the past I didn't look to try new things. Now I am happy to give anything a try, I go along to all the workshops. All the training I've done at LCiL has given me confidence to try new things. I got asked to sit in on interviews - I wouldn't have had the confidence to do that in the past.'

'Through the workshops and groups I have attended, I have felt respected, listened to and supported and have therefore been empowered to take steps to help myself.'

'From coming to the group and different workshops I am up for new challenges. I tried facilitation training which I found really difficult, but I am really glad I did it. I got a lot from it, skills that I can use in my work and in the groups and workshops.'

'In the sessions you get to hear from people who are doing things, this gives me encouragement to try things myself. Before it was all unknown to me and I was scared to try different things.'

'Where I lived was a barrier, I had almost given up. Every time I tried to access something, I was told no. After hearing no, no, no, I had stopped trying. LCiL opened that door up for me, by not only always inviting me to things and believing in me, but also providing transport so I could try new things!'

6. Working together with others for change (collective voice)

Before I was in a group		Now	
I didn't believe that things could be changed by working with others	•••	I don't believe that things could be changed by working with others	
I knew that there were possibilities for change	•••••	I know that there are possibilities for change	••
I was looking for opportunities to work with others to create change		I am looking for opportunities to work with others to create change	•
I had started working with others to create change, but this was difficult	•••	I have started working with others to create change, but this is difficult	•••••
I was encouraging and supporting others to create change by inviting them to join me/us	•	I am encouraging and supporting others to create change by inviting them to join me/us	••••
I was organising and leading action to support others to create change	••	I am organising and leading action to support others to create change	•••

Key points

People express a sense of:

- community, often speaking of 'our group' and 'our work'
- having a shared goal around changing attitudes to disabled people and a desire to do more and 'spread the word'

Some people have started to get involved in other organisations, groups or causes since they have been coming to peer support groups

'If opportunities arise to get the views of disabled people on things that will impact them, I tell others, try to get as many people involved as possible.'

'Before I became disabled I was interested in politics, but I never really got involved. That is very different now. I use my voice to speak up when I think something is wrong. I have attended a lot of consultations, because I want to get my voice heard. Unfortunately most of the time they feel like a tick box exercise. Have they actually done anything or taken action because of the consultation? Most of the time no.'

'I am now involved with Inclusion Scotland and jump at the chance to have my voice heard through consultations and discussions with people who make decisions.'

'Now I am part of LCiL I have a sense of community. I now stand up for my beliefs, especially when I know I am not wrong. I like being part of LCiL, we all support each other when needed.'

'Thanks to LCiL I am now very politically involved. I am an activist now, I attend rallies and events. I wouldn't have been able to do all this without LCiL, it reinforced something in me. It boosted my confidence and now I am no longer someone stuck in my house, afraid to voice my opinions.'

'In the past, I had tried to do things in groups that would work towards change or activism but it didn't work out. Because of my personality, other people often exclude me. This hasn't happened at anything I have involved with through LCiL. Here we are all equal, have a similar understanding and working for the same thing.'

What are you doing that you didn't do before?

'I ask for support when I need it. For example, I just approached Advocard to get advocacy support with the DWP. In the past I would have gone to the assessment by myself and been totally stressed out.'

'I am meeting lots of new people and making friends with people I wouldn't have ran into otherwise.'

'I stick up for myself, especially at work. I now go to my union for help to back me up, before I would have just let it go.'

'I now take time for myself and am more assertive about it, I have more focus. I less inclined to try and do everything by myself and everything for everybody. I try to push myself to attend things that I know will benefit me. Because of my mental health I still can't do a lot of things, I am still recovering, but I am accepting where I am at the moment.'

'I have joined the tenants' board of my housing association, so I am having my say there too.'

'Volunteering for LCiL. The one-to-one peer support has given me a massive boost. I feel like it could be a stepping stone to employment.'

'I've reached out to my family. I had purposely distanced myself since my accident. Now I want to reconnect with them and have relationships with them.'

'I get out of my house more! I felt trapped, now I am out and about going to different things.'

'I am much more organised with my life. I make an effort to sort my appointments out, I have responsibility now, so I am planning and getting more organised.'

In what ways do you feel different?

'I feel a lot more relaxed.'

'I feel stronger and less alone.'

'I feel better inside myself. I know that I can get more out of it if I know others have done it. When I hear that somebody else has done it I think maybe I can too.'

'Although I still have a lot of difficulties, I don't feel as much of a victim. I know that, instead of accepting the decisions other people make about me, I can and will challenge them.'

'I feel more fulfilled.'

'I feel empowered.'

'I feel like my life experiences and my opinions are valid, in the past I have been told the opposite.'

'I feel I know more about myself now, what my purpose is. I feel confident to share my experiences with others.'

'More confidence – I didn't like being around new people, they just saw the chair. It's changed my perspective.'

'I do have skills, abilities and something to offer! I didn't believe that before, this is a massive gift.'

'I feel like a more complete person. Society tells disabled people we are "less than", I can confidently tell anyone who believes that, that they are wrong.'

'I feel less frustrated.'

'I feel a lot more determined and assertive.'

What's happened as a result of the being in the group?

'I have made new friends and bonded with people who I don't think I would have got the opportunity to meet if it wasn't for LCiL bringing us together.'

'I got the idea to advertise myself as a volunteer through the Volunteer Centre. I have had a call from an organisation who thinks they could use my skills. It could open up more doors for me.'

'I ask for help – before LCiL was part of my life I wouldn't have known where to start or that I was even entitled.'

'I wrote to my GP to tell her I was re-applying for PIP and enclosed a list of my conditions and how they affect me, as I know she will be asked for a report.'

'I had qualified to teach a course through Action on Depression. Although I had the qualification, I had never taught it. I now really want to get out there and give it ago.'

'I was in serious debt because I wasn't getting enough benefits to cover my costs. It was really stressing me out, but LCiL helped me out of that. I wouldn't have known how to go about getting the help without LCiL'

'My time management is better. Just being invited to things has me out and about and this has impacted all other parts of my life. I now am in a routine; I can get out of my bed at decent time in the morning and achieve things during the day.'

'I could have just wallowed in the dark times, let my depression get the better of me. That doesn't happen anymore, the group helps me get through the dark times.'

What do you think makes the groups work well/not work well?

'Everyone is respected and no-one is put on the spot or made to feel uncomfortable/stupid.'

'People don't just talk about the negatives, you get to positives, things that people are going through. We always get to laugh even if things are bad for most of the people.'

'Facilitators say very little, and they don't come in with their own agenda. The group is user led. A lot of places say that they are this, it's easier to say and harder to practice. The peer support group gets it spot on, we own the group.'

'Having John [personal assistant] is a huge help.'

'The plan is flexible and allows participants to cover issues that are important to them.'

'Small groups – you get to know people, make friends.'

Feedback – [the facilitators] always ask for feedback, and always ask if there is anything else we need as a group.

'Well organised and structured. Very relevant information. Good mix of planned information sharing and time to hear about personal experiences. Very social and fun, not all heavy.'

'Lunch afterwards is important, you can carry on conversations.'

'I always feel included and people actually listen to me. Everyone gets a chance to talk.'

Elaine's story



'Probably the most important thing for me was that I felt less alone and I realised that I wasn't the only one having to endure these experiences.'

In 2014, an accident left Elaine with injuries that impacted heavily on her physical health and mobility, leaving her unable to leave her house for a year.

This impacted on Elaine's mental health and she was experiencing anxiety and depression.

Elaine had applied for both Personal Independence Payment (PIP), the benefit that helps with the extra costs of a long-term health condition, and Employment and Support Allowance.

She completed both forms and attended the face to face assessments by herself, as she did not know that support was available. Despite her obvious need, Elaine was turned down for both benefits and received nothing.

'Both of these were extremely degrading and traumatic for me. I received none of these benefits and I was forced to look for work. This led to my injury becoming even worse. I felt I had no voice and I wanted to be able to stand up for myself, so the workshop seemed ideal for me'

Elaine then attended the Know Your Rights workshop for people who want to improve their knowledge of their rights, increase their ability to self-advocate and learn how to make a complaint.

At the workshop Elaine learnt that she could re-apply for PIP and that LCiL's Grapevine Disability Information service would assist her to fill out the form.

'I found the workshop really helpful. Probably the most important thing for me was that I felt less alone and I realised that I wasn't the only one having to endure these experiences. I felt that I was listened to with dignity and respect and I didn't feel like a freak or an object of pity. I felt stronger after speaking to other people and I knew that I could get help to re-apply for PIP'

Elaine's story

A disability information officer from Grapevine guided Elaine through the application process, assisted her to fill out the form and organised an advocacy worker from a mental health advocacy project to accompany Elaine to the face to face assessment.

'I was really scared about the idea of another face-to-face assessment, but being at the workshop I learned I could have a mental health advocate come with me. I was still really scared, but I felt so supported by LCiL through the whole process that I was determined to keep going with it.'

Two months later Elaine was told that she would be awarded the enhanced rates for both the daily living and mobility components – a total of £139.75 per week.

'Getting the PIP made a huge difference to me and I can now have more counselling sessions than before and not worry so much about paying for private physio and taxis.'

'Within a very short period of time, I have gone from feeling really depressed and hopeless to knowing that things can and will get better, because I have the money I need to access all the services I need to.'

'When you are constantly worrying about making ends meet and struggling with physical and mental ill-health, it all becomes overwhelming. Having the ability to pay for the things I need has really made me feel better and the energy I was using worrying about everything is now being channelled into more constructive actions'

Elaine now volunteers with an organisation that she loves and is currently seeking part-time work. With the extra financial help from PIP she was able to cover the transport costs to attend a lifestyle management course. She continues to come to the LCiL peer support group.

'I feel so glad that I attended the workshop, because with the help of LCiL's Grapevine Service, I re-applied for PIP and was granted both elements at the higher rate!'

'I had let other people tell me "no" too often and I was too scared and squashed down by life to fight back. Attending the workshop and peer support group reminded me that I do have rights and that I had a right to get the help I needed.'

Part 2



Setting up and facilitating peer support

Sharing learning and materials

We hope the material on the following pages will give you enough information to set up a similar peer support group if you want to do so.

We are happy to share more detailed information and learning:

For organisations working within the four Lothian local authorities we can come and talk you through how to set up and facilitate workshops and/or peer support groups, work in partnership with you to deliver these, or run them for groups you're working with.

For organisations outside Lothian we are happy to speak to you on the phone to talk you through how to set up and facilitate workshops and/or peer support groups.

Please just get in touch if you would like to discuss any of the above.

Contact details

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A note on definitions:

Peer support is a system of giving and receiving help by understanding others' situation empathically through **shared experience**. It is founded on key principles of **respect, shared responsibility** and **mutual agreement** of what is helpful.

A workshop is a series of activities (information, skills practice, group discussion etc) designed and led by facilitators. Although part of the workshop may involve hearing someone's lived experience of the topic, learning, rather than peer support, is the primary purpose. In a workshop peer support will happen because the group is only open to people who identify as disabled people or people with long term conditions, and the workshop is designed and facilitated in ways which encourage peer sharing and peer support.

A peer support group has peer support as its primary purpose and the group makes all decisions about the format and content of the sessions, including whether or not the group is open to new members. The group may choose to ask an expert from outside the group to come in and speak to them on a subject or to give them information, but that invitation comes from the group and the timing of it is decided by the group. While facilitators may host the group it is owned and led by its members.

Beginnings

In the second half of 2015 we designed and ran a series of consultation sessions to find out what disabled people and people with long-term conditions wanted and needed in terms of development and peer support opportunities.

First, in partnership with our Champions, we developed and tested a consultation activity.

We used a revised version of this activity with LCiL staff from across our core services, in two groups, to find out what they were hearing from the service users they were working with.

We then created a two-hour service user consultation workshop and ran this with two groups.

At these sessions:

- a Champion gave an input into their own journey to becoming more empowered and confident
- we asked people what topics were most important and what order these should be delivered in
- we provided lunch afterwards to give people the opportunity to continue getting to know each other

This process – making sure lived experience is part of the session, involving people, asking them to make decisions and giving them time and space to socialise – set the tone for everything we have done since.

At the sessions people told us that workshops on: **‘information about what my rights are’** and **‘how can I make sure I can be heard and get my needs met’** should be offered first.

People also talked about needing **strategies to deal with ‘helpful’ or inappropriate suggestions from others**. The subsequent workshop title – ‘Have you tried God, or snake venom’ – came from a participant on one of the consultation sessions who said he was fed up being asked those questions!

We developed **an ethos** and set of **general principles** for designing and running workshops:

Workshops will be delivered in ways that encourage people to empower themselves

All workshops will include an input from someone who can share their lived experience of the subject matter

Workshops will be limited to a maximum of 10 participants to give everyone the opportunity to participate

During every workshop, participants will have the opportunity to:

- take something away (skill, knowledge, insight etc)
- plan how to use what they're taking away
- leave ready to use what they're learned
- tell us what else they would like sessions about

All workshops will:

- include context about the social model of disability and rights of independent living
- explicitly name power, and power imbalance as an issue
- lead to other capacity building workshops, LCiL training or peer support opportunities, and will signpost people to these

We then designed and ran:

- **Know Your Rights**, three times between September 2015 and February 2016
- **Assertive Communication**, twice between October 2015 and February 2016.
- **Have you tried God, or snake venom?** once in March 2016.

(See Appendix 1 for descriptions of these)

We have continued to run these three workshops regularly.

Setting up the first peer support group

At the initial workshops we asked people if they would like to meet as a **peer support group**. There was an enthusiastic response and the group met in Edinburgh for the first time in February 2016 and has met every month since.

At the initial meeting:

- we asked the group what their individual hopes were
- they created a set of guidelines that they agreed to work to
- we discussed what they wanted in terms of structure, duration and so on:
 - day of the week, time of day, frequency and duration
 - open or closed
 - structure – open time to catch up and/or time to hear from expert speakers or do development activities

The participants decided the group should:

- always be open to new people
- meet monthly alternating between Tuesday and Thursday to allow people with other regular commitments to come at least every other month
- run from 10.30 to 12.30, with lunch after
- always have a slot of time for people to share information or give and receive emotional or practical support
- have expert input or other activities decided on a month by month basis when a topic or issue arose from the group

They agreed to try this format and review after six months.

From the second session onwards we used following sequence of events at each session:

- Coffee and settling in
- Housekeeping, round robin of introductions
- Brief icebreaking conversation in pairs
- Catch up time
- Guest speaker or development activity (if requested)
- Review and 'what next'
- Lunch

After a few months we had enough people coming from West Lothian to set up a group there, rather than people travelling into Edinburgh. This group has met monthly since August 2016.

Group guidelines

- Respect confidentiality – what's said in the room, stays in the room
- Respect others and their feelings
- Listen to others – actively listen
- Interact at your own pace
- Agree to disagree – respect others' opinions
- Don't assume you know what's someone's going through
- Don't interrupt
- Ask if you don't understand – there are no silly questions
- Come as you are – however you're feeling
- Speak kindly – 'you might', not 'you should'
- Welcome people, however they are
- Don't judge, keep an open mind
- Say how you're feeling
- Think kindly, mindfully
- Ask for what you need, and you don't need to wait for breaks if you need something
- Let folks be
- Phones off unless in an emergency
- Introduce new people, update them

Group hopes

- Acceptance, not having to hide, spending time with others in the same boat
- Make friends and meet new people
- Give others my experience
- Get support from organisations
- Curiosity – what will I receive from this?
- Survival – interact with the world and others in a helpful way
- Know I'm not alone
- Talk to others with similar problems
- Allow myself to be here just for me
- Help me, not just try to help others
- Gain some confidence and find some trust
- Think forward, not backward – discuss hopes and dreams and where I'm heading
- Not having to constantly explain myself

Hosting and facilitation

LCiL staff host the group by booking rooms, refreshments and lunch and finding and inviting guest speakers, if required. We book taxis for those who need them and make sure there is a PA who can take care of practical needs of group members – this allows everyone, including the facilitators, to focus on the conversations people are having.

LCiL staff also facilitate the sessions so that people can just come along and take part, knowing that the process and practicalities are taken care of. Group members do the majority of the talking; they are the experts and are there to share information and support with each other. As facilitators we only step in to:

- ask questions to clarify something somebody has said
- identify key points
- give information, if and when appropriate
- manage the group process: ensure everyone gets the opportunity to speak and are kept to time, check where the group wants the emphasis put if timings need to change (for example because someone has something difficult or complex they need support with which takes up a lot of time)

The facilitators are not peers of the group members. This has advantages: as non-disabled people we can stay objective about issues and difficulties because we don't share those experiences – we can concentrate on holding the group and supporting people to do and say what they need to.

We serve and offer expert advice (for example by designing activities that the group have asked for to explore a particular topic or skill, or explaining SDS or local authority processes), but we don't own the group, and we're not members of it.

We need a high level of awareness and good skills at reflecting on our own behaviour to make sure we don't cross into taking control, especially when working with people who are frequently disempowered by social care, benefits or NHS systems. Regular reflection on our own practice and conversation with group members to make sure we aren't drifting into 'doing things to' the group, or making decisions on its behalf, are vital.

Building trust with people is also vital if this is to work – without trust group members are less likely to be honest if things aren't working, or to be able to say no to suggestions that they don't like. Without trust between facilitators good, constructive feedback and reflection on practice is difficult or impossible.

Action learning

From the start we decided that we needed to try things out, reflect and adjust what we did and how we did it as we went so that we could give people what they needed. We knew that we didn't know exactly how to do this and would need to consult, involve and experiment in order to find out.

This way of working is in part an **attitude** and in part a **set of actions** – for example:

- at workshops we always ask for feedback about what worked, what didn't work and what would make it better for next time (see appendix 2 for the form we use)
- at peer support groups we ask 'what other topics do you want to look at/information about?' and 'how is this format working?' We do this both at each session and more formally every six months or so.
- we also reflect after each workshop or peer support group session, asking ourselves 'what could we do differently/more of/less of?' and act on that
- we carry out a formal evaluation periodically (this report details the first of these)

All of this reflection, consultation and evaluation forms a cycle of learning and action. We expect to continue to do this for as long as the workshops and groups continue to run.

What we've learned so far

We needed to be very flexible and park our expectations – for example:

- we might expect that a small group would be easier to facilitate than a large one – this often turned out not to be the case.
- we thought we'd learned a lot from facilitating our parent carer peer support group, but found that people in this new group wanted more time to catch up with each other and less input from guest speakers, and the group felt completely different
- the Open Space¹ facilitators' rules are useful here:
 1. Whoever come are the right people
 2. Whatever happens is the only thing that could have
 3. Whenever it starts is the right time
 4. When it's over, it's over

¹ OpenSpace is a set of rules that allow groups of people (even very large groups) to interact in a simple, productive, organized way to create valuable dialogues that address the participants' most important issues.

We moved to asking at the start of the catch up 'who has something they want to talk about/get help with?' so that we could manage the time better and make sure no one got left out.

Partly because people had said that they wanted to talk about positives and partly because of the Good Conversations training we participated in (see 'support for the process' section), we started using '**what matters to you?**' in some form as the icebreaking conversation at each session. As well as giving people the opportunity to talk to at least one other person before speaking to the whole group (a daunting prospect for some) this gives people the chance to think about what matters rather than only talking about what's not working.

Group members had decided that the group should always be open to new people, and that people can dip in and out. This means that:

- time has to be spent at each meeting doing introductions
- time to work on a specific issue or topic can be very limited
- people may not go as deep as they might in a closed group
- sometimes the person who proposed a topic one month isn't there the next time when it's being discussed

Because of this we asked the group if they would be interested in a closed, time-limited group to work in depth on a topic. They said yes and we developed a six session **linked peer support group** focussed on 'getting unstuck', the topic they chose. This group was successful and we have since offered a second group, 'ways into work', a topic that was a recurring theme for people in both the Edinburgh and West Lothian groups. The learning from these will be reported on separately.

Support for the process

Adequate, long-term funding is needed to run groups consistently and make them accessible to as many people as possible:

- good, accessible venues, lunch and transport by taxi all cost money but make a significant difference both to how group members feel valued and to staff being able to focus on the group rather than the practicalities
- staff have time and space to reflect, experiment and evaluate

The way that funders manage their funding programmes makes a difference too – Scottish Government have been very flexible, allowing us to do proper development work; we have been asked to report on the outcomes that have been achieved, rather than having to say up front exactly what we will achieve. This has allowed us to follow what the people we're working with and for want, rather than trying to push them

into programmes and events to try and meet outputs and outcomes set out months or years earlier.

As staff we have benefitted from skills development and reflection opportunities:

- **Good Conversations** – a two-day course to build confidence in holding outcomes focused conversations, and moving from an ‘expert stance’ to being a facilitator in a variety of common and difficult situations.
- The learning set **Making it Happen – leading the SDS change** where a group of managers with responsibility for development work around Self-directed Support participated in a series of coaching and reflection sessions (itself a form of peer support)
- Using the **A lasting difference** sustainability toolkit, both with a facilitator and on our own to reflect on our work

Again, these opportunities and the time and space to reflect and make changes to our practice are vital to being able to continue to focus on the evolving needs and wants of the people we’re supporting and serving.

Assertiveness 1 workshop description

3 hours, maximum of 10 participants

Learning outcomes

At the end of the session participants will have:

- ✓ better understanding of different ways of communicating, and their effects
- ✓ improved skills in assertive communication
- ✓ increased confidence

Workshop content

- Aggressive and passive communication and their effects
- Assertive communication and how to use it – participants will have the opportunity to try it out
- Each person will be able to plan how to make a case, and to communicate this assertively, using a real situation from their life

Workshop style

- Participative
- Informal and relaxed
- People will have the opportunity to draw on their own experience, but can choose how much they share with the rest of the group
- Brief input from facilitators, backed up by short, easy to understand written handouts

Who for?

Disabled people/people with long-term conditions who:

- want to become more assertive
- are preparing for an assessment
- want to challenge the outcome of a decision

Leads to:

- Assertiveness 2 – people return to review how they put their skills into practice, deepen self-awareness and skills
- But people can do Assertiveness 1 as a standalone

Assertiveness 2 workshop description

Note: participants must do Assertiveness 1 before doing this workshop

3 hours, maximum of 10 participants

Learning outcomes

At the end of the session participants will have:

- ✓ better understanding of how feelings relate to assertiveness
- ✓ increased self-awareness
- ✓ improved skills in assertive communication
- ✓ increased confidence

Workshop content

- Review of practice since Assertiveness 1
- Feelings and their effect on confidence – comfort and learning zones
- Participants will have the opportunity to replay any situation that didn't go so well since session 1, with support and feedback from the group
- Each person will be able to make a new plan, incorporating what they've learned from this session

Workshop style

- Participative
- Informal and relaxed
- People will have the opportunity to draw on their own experience, but can choose how much they share with the rest of the group
- Brief input from facilitators, backed up by short, easy to understand written handouts

Who for?

Anyone who has taken part in Assertiveness 1 and wants to

- deepen their self-awareness
- continue to increase their skills

Know your rights workshop description

3 hours, maximum of 10 participants

Learning outcomes

At the end of the session participants will have:

- ✓ better understanding of their rights, and how these are underpinned by the social model of disability
- ✓ increased confidence
- ✓ knowledge of where to go for support/advocacy with accessing benefits and services

Workshop content

- Social model of disability and human rights, delivered by an LCiL Champion
- Where and how to get support
- When to 'do it yourself' and when to get support
- When and how to complain

Workshop style

- Participative
- Informal and relaxed
- People will have the opportunity to draw on their own experience, but can choose how much they share with the rest of the group
- Input from facilitators and peers
- Participants will be given a written 'handbook' with information, 'top tips' and contact details

Who for?

- Disabled people/people with long-term conditions who want to improve their knowledge in order to self-advocate

Leads to Assertiveness 1 (though people could also do assertiveness workshops first)

Have you tried God, or snake venom? Workshop description

3 hours, maximum of 10 participants

Learning outcomes

At the end of the session participants will have:

- ✓ better understanding of own and others' motivations
- ✓ increased confidence
- ✓ increased skills in having 'difficult' conversations

Workshop content

- social model of disability
- stages of empowerment
- dealing with own response to people trying to be 'helpful'
- how to turn the conversation around to educate/change attitudes – participants will have the opportunity to replay a situation from their own life

Workshop style





- Participative
- Informal and relaxed
- People will have the opportunity to draw on their own experience, but can choose how much they share with the rest of the group
- Brief input from facilitators, backed up by short, easy to understand written handouts

Who for?

- Disabled people/people with long-term conditions

Leads to Assertiveness 1 (though people could also do assertiveness workshops first)

Name: _____

Thinking Hat	Comments
 <p>Red Hat Your gut reaction, how you feel about today</p>	
 <p>Yellow Hat What worked, you enjoyed, was fun or interesting</p>	
 <p>Black Hat What didn't work, you didn't enjoy, or was boring</p>	
 <p>White hat What was missing?</p>	
 <p>Green Hat What would improve it for next time?</p>	

LCiL works with disabled people, people with long-term conditions and older people, parents and carers in Edinburgh and the Lothians.

We support people to:

- live more independently
- be more in control
- use self-directed support

We are a user-led disabled people's organisation, and a registered charity.

We're part of the Independent Living Movement and we work with disabled people to take control of their own lives, support their choice to take up their rights and enable their full participation in society.

Our services are designed and delivered by disabled people.



Information and one-to-one support to help people manage their own self-directed package.

Wages processing and administration for people who employ their own personal assistants.

Financial Management Service to help people budget and plan, make payments and manage paperwork.



Free, confidential disability information and advice for people in Edinburgh

Lothian Centre for Inclusive Living
Norton Park, 57 Albion Road
Edinburgh, EH7 5QY

0131 475 2350 (10am – 4pm)

lcil@lothiancil.org.uk

www.lothiancil.org.uk



Lothian Centre for Inclusive Living